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ABSTRACT

The study examined agreement and disagreement between 24 adolescents (age 15-20) with chronic illness and their mothers on questions relating to the adolescent's transition into adulthood. The subjects were divided into two groups: one with mobility impairments and one with general health impairments. Areas examined included health, finances, work, living arrangements, recreation, mobility, communication, self-care, and socialization. Significant differences were found between: (1) adolescents with mobility impairments and their parents regarding whether they would have health problems as adults; (2) adolescents in each group and their parents regarding whether they expect to have children; (3) adolescents in each group and their parents regarding whether or not they had knowledge of financial programs and/or agencies. Seventy-five percent of the adolescents felt that they could fully support themselves as adults, while only 33% of the mothers of general health-impaired adolescents and 67% of the mothers of mobility-impaired adolescents felt so. Compared to the general health-impaired adolescents, more adolescents with mobility impairments and their mothers identified a need for special living arrangements as adults. Future normal employment was agreed upon by adolescents and their mothers. (40 references) (JDD)

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TRANSITION NEEDS FOR CHILDREN WITH CHRONIC ILLNESS INTO ADULTHOOD: ALLEVIATING THE CONCERNS OF FAMILIES WITH INFORMATION AND KNOWLEDGE

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ABSTRACT

The purpose of this pilot study was to examine agreement and disagreement between adolescents (15 to 20 years) with chronic illness and their parents on questions relating to the adolescent's transition into adulthood. Topic areas included health, finances, work, living arrangements, recreation, mobility, communication, self-care, and socialization. Significant differences, although speculative due to the small numbers, were found between: (1) adolescents with mobility impairments and their parents regarding whether they would have health problems as an adult, (2) adolescents in each group and their parents regarding whether they expect to have children, and (3) adolescents in each group and their parents regarding whether or not they had knowledge of financial programs and/or agencies. Responses to the other questions illustrated that these families continue to need information and referral regarding all aspects of their lives indicating that these needs are not currently being met by the educational and health care systems.

TRANSITION NEEDS FOR CHILDREN WITH CHRONIC ILLNESS INTO ADULTHOOD: ALLEVIATING THE CONCERNS OF FAMILIES WITH INFORMATION AND KNOWLEDGE

The needs of the homeless, unemployed, cultural minorities and the developmentally disabled often provide the headlines for the daily news stories. Although the population under 18 consists of 10-15% of persons with chronic illnesses, the needs of this group have largely been ignored. This may be a result of public disinterest and/or ignorance of the specific and unique concerns and needs of this population. Specifically, the years between adolescence and adulthood are a difficult transition for any person, but this period of time provides a special challenge for youths with chronic illness. The effects of chronic illness on the adolescent and his/her family during this transition affects every aspect of their lives.

Health

Typically, illness and well-care visits to the doctor are less frequent during the adolescent and young adult years. Health care is reserved for school and sports physicals and any sports injuries. This is not so for the person with a chronic illness.

Pless and Pinkerton (1975) have defined a chronic illness as "a health condition that lasts for more than three months in a year and that leads to continuous hospitalizations for at least one month in a year (p. 3)." It is estimated that there are 7.5 million children in the United States with a chronic health condition, of which 1.3% of these children are severely affected.

Specifically, Smyth-Staruch and her associates (1984) found that children with chronic illness used health services ten times as much as the child without health problems and the costs were also ten times as much. Visits to doctors overall occurred three times as often with visits to specialists happening twice as much. Hospital days per year further occurred twice as often with a mean of 17.3 days and the overall mean length of stay was found to be 11 days. In regards to specific diagnoses, in a sample of children with cystic fibrosis, cerebral palsy, spina bifida, and multiple physical handicaps, children with cystic fibrosis made the most number of doctor visits.

Liptak and Revell (1989) in a study comparing doctors and parents who have children with

chronic illnesses, found doctors routinely underestimated the parent's need for information regarding the child's diagnosis (8% versus 52%, $p<.001$), treatment (3% versus 52%, $P<.01$) and prognosis (30% versus 78%, $p<.01$). Also, the doctors overestimated the parent's need for information about financial aid (70% versus 58%, $p<.01$), vocations (78% versus 54%, $P<.01$) and insurance (62% versus 51%, $p<.05$). When asked what the level of communication was between the doctors and parents, the doctors responded fair and the parents poor.

The parents remarked that they felt specialty clinics were more informed about community services than either the community doctor or the schools, and even though they may have to travel to the specialty clinics, the specialty clinics and the community doctor were equally accessible. The doctors surveyed in this study also agreed that specialty clinics knew more about community resources (Liptak & Revell, 1989).

Parents specifically listed respite care, parent support groups, help with behavior problems, financial information or help, vocational counseling and psychosocial services as most important to them. They also requested more information on community resources, recreational opportunities, summer camp, and dental treatments (Liptak & Revell, 1989).

It is evident that a large number of adolescents and young adults in the United States have a chronic illness. These persons require an increased amount and variety of health and related services. Past research has found that doctors and parents disagree on the quality and types of services rendered. No studies on any other disciplines were found regarding quality and quantity of services to families with a member with a chronic illness. Further research is warranted in this area as well as increased training, communication and support by present doctors and other professionals who care for these families.

Financial

Financial issues will arise in these families due to the increased health care costs which will incur over the lifetime of the child. McManus, Newacheck and associates (1989) examined health insurance status of adolescents and young adults in the United States using the results of the 1984 National Health Interview Survey (Newacheck, 1989; Newacheck & McManus, 1989; McManus, Greaney

& Newacheck, 1989). Among the adolescents, 4.5 million or 14% were uninsured. Specifically, 74% of the adolescents surveyed had private insurance, 10% had public aid, and 2% had a combination of private insurance and public aid. Cost and loss of employment were the primary reasons for no insurance cited by 70% of those adolescents without insurance. Parental educational level, disability (including activity limitations), and poverty level also increased the chance for no insurance coverage (Newacheck, 1989; Newacheck & McManus, 1989).

Of the young adults surveyed in 1984, 65% had private insurance, 7% had public aid, 1% used a combination of private insurance and public aid and 26% or 6.4 million had no insurance. Due to child-rearing, 9% more women than men had some form of insurance coverage. Furthermore, poverty level, educational level, health impairment, and employment status were factors which influenced presence and type of coverage. The authors emphasized that this is the age group at greatest risk for being uninsured. They listed lack of information regarding health insurance, lack of qualification for private health insurance or Medicaid, cost, and priority as reasons for the absence of health insurance in this age group (McManus, Greaney & Newacheck, 1989).

In the more recent National Medical Expenditure Survey, 1987, Short, Monheit and Beauregard (1989) found numbers of adolescents and young adults without insurance greater than those reported by McManus, Newacheck and associates. Numbers such as these should alarm the public. It is also imperative that professionals and public policy makers have an understanding of the costs incurred by families with a member with a chronic illness. More statistics and planning towards better and increased financial alternatives need to be initiated in across the country.

School

Children who are hearing-impaired, chronically ill or orthopedically impaired accounted for approximately 6% of the total special education population in 1987. These groups of children were also the most costly to the school system, costing an average annual cost of approximately $10,000 per child (Butler, Palfrey, Singer, Walker & Raphael, 1988).

Researchers have found that 77% of the orthopedically impaired and 65% of other health

impaired adolescents graduate from high school. Fifteen percent of the orthopedically impaired and 25% of the other health impaired teens dropout. Limited stamina, attitudes of others, medicine side effects, missed medications, psychosocial concerns and expectations can lead to school problems and absences. Also, lack of knowledge and resources regarding chronic illness by school personnel, peers and teachers, and structural limitations in the school exacerbate the problem (Weitzman, 1984).

Most adolescents with a chronic illness do not go on to attend college. In a recent study, Evangelauf (1989) found only about 15% attend college. Further research is needed to ascertain more accurate numbers of individuals with different chronic illness and their attendance in post-secondary institutions. Reasons for choice of institution, dropout, additional services and psychosocial adjustment need to be covered.

Work

With only 15% of disabled teens attending post-secondary schools, most persons with a chronic illness should be entering the workforce. This is not true, only 21% make a successful transition from school to work (Hippolitus, 1985). Only 31% of those adolescents with a chronic illness enrolled in special education classes get any vocational planning and those teens not in special education are often absent due to health-related reasons and their school schedules are altered to include the basic courses excluding vocational education (White, 1989).

Hippolitus (1985) emphasized that the lack of employment may be due to the vocational educator's lack of knowledge regarding chronic illness and the employment potential of these youth. An essential lack of role models is also present. Castree and Walker (1987) found that mobility was the major liability in adolescents with spina bifida's efforts to find employment. They felt that employers were hesitant to hire youth with spina bifida due to: (1) increased costs of health insurance, (b) major structural changes needed in the workplace, and (c) attitudes of other employees. In the same light, Allen (1985) found in the case of persons with congenital heart defects, that employers equated that diagnosis with heart attack and feared employment of that individual.

Fear and misunderstanding continues to combat the adolescent with a chronic illness attempting

to obtain employment. Further research and descriptions of model programs which employ this population need to be discussed.

Psychosocial

Researchers and clinicians have argued whether the presence of chronic illness creates psychosocial problems. Whitt (1983) wrote that, as a group, these persons have a greater frequency of maladjustment and that age at onset, severity, progression of the disease, personality, IQ, coping and family dynamics are just a few of the variables which can affect the quality of life. Other writers have agreed, commenting that youth with chronic illness have a lower self-esteem, feelings of helplessness (McAndrew, 1979; Blum, 1983), distorted body image, increased awareness of future and death (Boyle, deSant-Agnese & Sack, 1976), lack of confidence, less social maturity (Lineberger, Hernandez & Bramtley, 1984), and increased behavior problems (Gortmaker, Walker, Weitzman & Sobol, 1990). On the other hand, other researchers have found no psychosocial sequelae in youth with chronic illnesses (Zeltzer, Kellerman, Ellenberg, Dash & Rigler, 1980; Kashani, Barbero, Wilfley, Morris & Sheppard, 1988).

Studies have specifically examined the psychosocial development of adolescents with specific chronic illnesses. Youth with cystic fibrosis were found to feel that their health was controlled from the outside (Kellerman, Zeltzer, Ellenberg, Dash & Rigler, 1980), had a poorer adaptation if first-born (Mador & Smith, 1988), experienced increased denial as they became older (Strauss & Wellisch, 1981), and had a tendency for depression (Bywater, 1984).

Adolescents and young people with spina bifida have been reported to have lower self-esteem (McAndrew, 1979; Blum, 1983), social immaturity (Blum, 1983), and increased levels of anxiety (Kuzak, 1986). Factors predicting poor psychosocial adjustment in persons with juvenile rheumatoid arthritis included internal and external behavior problems, the family psychosocial environment, health status, chronic musculoskeletal pain (Litt, Casky & Rosenberg, 1982; Varni, Wilcox, Hanson & Brik, 1988), length of morning stiffness, social support and hardiness (Lambert, Lambert, Klipple & Mewshaw, 1989).

Moreover, youth with cerebral palsy have been reported to have lower levels of self-esteem

(Magill & Hurlbut, 1986). Finally, adolescents and young adults with hemophilia have been found to have increased levels of self-doubt, decreased levels of compulsure (Webb, Wery & Krill, 1985), a sense of discouragement and helplessness, decreased social interactions, increased anxiety, decreased social maturity and confidence, and felt less parental affection (Lineberger, Hernandez & Bramtley, 1984).

These concerns have influenced friendships and expectations for marriage and child-bearing (McAndrew, 1979). Individuals with chronic illness and their families need to have increased information and planning regarding sexual development, interpersonal skills, genetic counseling, future planning and emotional support (Blum, 1983). These concerns should not be excluded in the care of these persons.

In summary, the transition needs of adolescents with chronic illness are many. Beyond the normal developmental tasks for this age group, inter- and intrapersonal factors can wreck havoc with the individual's attempt to live life with the best quality. Educational, health-related and psychosocial interventions and research are warranted for this population during this time when healthy and successful transitions are being highlighted. A pilot study of adolescents with chronic illness and their mothers was completed to assess agreements and disagreements regarding present and future expectations of the adolescent's life.

Subjects

Twenty-four adolescents (aged 15 to 20 years) and their mothers were obtained from the files of the Illinois Division of Services for Crippled Children and were living throughout Illinois. The subjects were divided into two groups: mobility-impaired and general health impaired and equal numbers were sampled from each group. Specific diagnoses of the subjects included: cerebral palsy (6), systemic lupus erythematosus (5), spina bifida (3), cystic fibrosis (3), juvenile rheumatoid arthritis (3), scoliosis (2), VonWillebrand's disease (1), dermatomyositis (1), and skeletal problems (1). One subject had two diagnoses.

Methodology

All 48 subjects completed a telephone survey requesting information on the adolescent's present

and projected conditions and activities regarding health, finances, work, recreation, mobility, communication, self-care and socialization. The questionnaires were completed between November, 1989 and January, 1990. The average length of time for each interview was 10 to 15 minutes.

Analysis

Due to the small subject size, crosstabs, chi squares and frequency distributions were completed. Analyses were done using the SYSTAT statistical software package (Wilkinson, 1988).

Results

A few demographic questions were asked. Results showed that 75% of the adolescents had or were attending special education classes [58% mobility impaired (MI) and 17% general health impaired (GHI)]. None of the subjects were mentally retarded. The majority of parents in the MI group had attended college (50% of the mothers and 58% of the fathers) and the majority of parents in the GHI group had attended high school (50% of the mothers and 58% of the fathers). Highlights of the study results are described in Table 1.

Health. Mothers and adolescents agreed that their current health status' were stable (87.5% of the mothers to 92% of the adolescents). Mothers of adolescents with GHI saw their child as sicker and in need of more health care. Mothers of adolescents with MI did not view their child as having health problems, but rather differentiated health from physical problems. Yet, when asked if they felt health problems would exist in adulthood, mothers and adolescents with MI differed significantly ($X^2=7.643$, $p=.022$) with mothers feeling health problems would exist in adulthood. Significant differences were not found between adolescent's and their mother's perceptions of present and expected future health needs. Health care resources also differed between mothers and adolescents. Mothers spoke most often to the specialty doctors in both groups and the adolescents spoke with their families. The specialty doctor was mentioned by adolescents only in the GHI group.

Finances. Further financial assistance for daily living needs and/or specific needs such as college was a major concern for all families. Seventy-five percent of the adolescents in both groups felt that they could fully support themselves as adults. The mothers were less optimistic. Only 33% of the mothers

Table 1. Highlights of Questionnaire Findings (in percentages)

	Adolescent		Mother	
Subject	MI	GHI	MI	GHI
Demographics				
Attended Special Education	58	17	58	17
Health				
Health Currently Stable	92	83	92	92
Future Health Problems	42	58	58	75
Finances				
Support Self as Adult	75	75	67	33
Need Governmental Support	42	58	58	83
Living Arrangements				
Will Need Special Arrangements	58	25	75	25
Work				
Will Work Full-time	75	75	67	83
Has Had a Job	67	58	75	75
Recreation				
Current Problems	42	42	42	67
Future Problems	42	42	50	67
Communication				
Current Problems	8	0	8	0
Future Problems	8	0	8	0
Self-Care				
Current Problems	58	17	58	8
Future Problems	50	17	50	8
Socialization				
Current Problems	25	0	17	17
Future Problems	17	0	8	17
Will Get Married	92	83	67	67
Will Have Own Children	67	75	8	8

with adolescents with GHI compared to 67% of the mothers with adolescents with MI felt that they could fully support themselves. On the other hand, adolescents felt that they would need governmental financial assistance by 42% of the adolescents with MI and 58% of the adolescents with GHI. Fifty-eight percent of the mothers with an adolescent with MI and 83% of the mothers with adolescents with GHI felt governmental financial assistance would be needed.

Currently the adolescents with MI and their mothers identified that their major financial support was out-of-pocket (75% and 83% respectively). Whereas, the adolescents with GHI and their mothers identified out-of-pocket (67% and 58% respectively) and private insurance (both 58%) as major financial supports. Other forms of financial support listed were the Division of Services for Crippled Children (DSCC), Social Security Income (SSI), Department of Children and Family Services (DCFS), Comprehensive Health Insurance Program (State of Illinois insurance program), Department of Rehabilitation Services (DORS), Medicaid, United Cerebral Palsy and the family. These resources were also mentioned for future as well as college financial aid departments.

When asked if they had any knowledge of financial programs, the adolescents as a whole differed significantly from their mother's responses (X^2=9.849, p=.007) with 42% of the mothers affirmatively answering and only 4% of the adolescents saying "yes." Specifically, the mothers and adolescents with MI differed significantly (X^2=8.00, p=.018) with 50% of the mothers saying "yes" they knew of a program(s) as opposed to none of the adolescents who could identify a financial aid program. Furthermore, neither mothers nor adolescents significantly identified any persons that they used as financial resources.

Housing. As expected, more adolescents with MI and their mothers identified a need for special living arrangements as an adult (58% and 75% respectively). Only one quarter of the adolescents with GHI and their mothers stated that this would be a need. Regarding where they felt they would live as adults, 83% of the adolescents with MI and their mothers agreed that they would be independent and 92% of the adolescents with GHI and 58% of their mothers felt independence was in their future. Reasons given by the mothers of adolescents with GHI as to why they felt they would stay at home were health,

life expectancy and dependence. Most of the subjects did not mention anyone as a housing resource as many did not identify this as a priority.

Work. Overall, future normal employment was agreed upon by adolescents and their mothers. Thirty-three percent of the mothers with adolescents with GHI saw no employment in the future due to their child's health, whereas all of the adolescents foresaw that they would be employed at least part-time. College was chosen most often as the adolescent's plans after graduation from high school.

Most of the adolescents also stated that they had already held at least a part-time job (67% for the adolescents with MI and 58% of the adolescents with GHI). Those who had not held jobs stated that this was due to school and/or health reasons. Current jobs were those expected of adolescents, jobs in sales, office work and labor.

Moreover, barriers to getting a job were listed by mothers. Many adolescents did not foresee any problems. Barriers included other's attitudes, health, employer discrimination, wheelchair accessibility, ability to get health insurance and physical condition.

Most of the subjects identified the high school's guidance counselor as serving as a work resource. Family members, friends, college career centers, school staff and teachers were also mentioned by both the adolescents and their mothers.

Recreation. Approximately half of the adolescents and their parents perceived that current and future problems in recreational participation would/does exist. This differed most in the GHI group with mothers and their adolescents feeling that recreational participation is and will be difficult in the future (67% and 42% respectfully). Individuals used for recreational resources included family, friends and teachers.

Mobility. All but one adolescent with GHI did not need any assistive devices to ambulate. That individual used a wheelchair without assistance to move about with. Adolescents with MI most often required a wheelchair without assistance (75%). Most subjects did not need any resources concerning mobility, but when they had, the adolescents with MI and their mothers had talked with family, friends and school teachers.

Communication. Only one adolescent with a MI was identified as having a communication problem. This family used their speech therapist as a resource.

Self-Care. More adolescents with MI and their mothers agreed in identifying problems in areas of self-care now and in the future (58% had problems currently and 50% stated they might in the future). Less than 20% of the adolescents with GHI and their mothers felt they had self-care problems now and in the future (8% and 17% respectfully). Family members and school teachers were used as resources for self-care needs.

Socialization. Twenty-five percent of the adolescents with MI believed that they had social problems now and 17% felt they would in the future. Only 17% of their mothers felt their children currently had social problems and 8% felt future problems would persist. None of the adolescents with GHI felt they had or would have social problems. Seventeen percent of their mothers felt their children with GHI had and would have social problems. Less parents in each group saw their child getting married in comparison to their adolescent's responses (83% of the GHI adolescents and 92% of the MI adolescents compared to 67% of both groups of mothers). Significant differences were found between mothers and their adolescents in both groups regarding whether they felt they would have children. In the MI group, 8% of the mothers said their children would have their own children and 67% of the adolescents felt they could have children (X^2=8.778, p=.012). In the GHI group, 8% of the mothers also said that their children would have their own children, whereas 75% of the adolescents felt that they could have their own children (X^2=10.978, p=.004). Again, family, friends and school teachers were used as resources along with the specialty doctor.

Most Used Resource. Subjects were asked who they turned to most regarding the future of the adolescent. The adolescent with a MI stated their parents (25%) and no one (50%). Their mothers indicated their spouse (25%) and no one (25%). Adolescents with GHI indicated no one (33%) and their parents and friends (each 25%). Their mothers mentioned their spouse (42%) and no one (33%).

Use of Programs. In each category except health, subjects were asked if they knew of programs/agencies where they could or did get information and/or referral. Information was at least requested in every

category with financial, work, housing and recreation most important for the adolescent and financial, work, socialization and recreation most important for the mothers. Identification of programs/agencies was much decreased by both adolescents and their mothers, although the mothers were able to identify more. Mothers listed more programs in the areas of finances and work (42% and 46% respectfully) and adolescents listed programs concerning work (29%). A combination of federal, state, county, and local governmental, hospital-based, educational, post-secondary, and private industry-based programs were listed in the categories.

Discussion

Findings from this pilot study illustrate that youth with chronic illness have many needs which will influence their transition into adulthood. These needs impact upon every aspect of their lives. Overall, the adolescent and their mothers agreed upon these needs and their expectations for the lives of the adolescents as adults.

Based upon their chronic illnesses, health will always be an issue. For the most part, information, medical care and expected health status were well understood by families.

Although financial resources could be identified, actual attainment of these funds were very uncertain. Information and positive contact with funding agencies/programs were ardently requested.

Special housing arrangements were specifically described as wheelchair accessibility and the use of attendants. Some families were already making the structural changes in their homes. Requests for information were for specific industries who did the structural changes (e.g., accessible shower).

Another area well thought out was in the area of work. In this category, the adolescents were clearer about their career choices and the people and directions they would take to meet these goals. Only in a few cases where the adolescent's health was precarious did the mothers probably have a more realistic expectation.

Programs were lacking for adolescents and young adults who were in wheelchairs. Many of the adolescents with MI and their mothers commented on this omission and also stated geographic location and transportation as other problems to participating in recreational events/programs. Subjects with MI

often stated that the special recreation programs available were only for individuals with mental retardation.

Most families who had mobility and communication concerns were dealing with these issues and did not need much additional assistance. Information regarding van and car alterations were most requested.

Families felt in control of the adolescent's self-care needs also. For most adolescents and mothers who mentioned problems in this area, more than one area of self-care required assistance. Specific concerns by mothers in this area included who would take care of the child when something happened to the parents. This issue also arose under the category of future housing.

Socialization was an area where most adolescents and mothers felt they could take care of any problem(s) by themselves. In some instances, mothers felt that ore friends and the availability of handicapped friends would be helpful. Overall, adolescents were content with their social lives, but those in wheelchairs would like opportunities to get out more.

It is interesting to note that more resources, both organizational and personal were not identified. A better effort by health organizations and school systems must be accomplished to identify these needs for each individual family and work to meet them, not just give the family "the run around." This process must involve follow-up too. At the minimum, information can be given as most all of the subjects requested information in most all areas. Efforts are underway to aid in the medical transition of these youth from pediatricians to internists. Such models need to be translated into the educational, financial, work, recreational and self-care arenas. A concerted interagency approach is needed. Awareness and opportunities for adolescents with chronic illness must begin.

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